CABINET FOR HEALTH SERVICES

Commission for Children with Special Health Care Needs

Health and Development Division

(Emergency Amendment)

911 KAR 2:120E. Kentucky Early Intervention Program evaluation and eligibility.

RELATES TO: 20 USC 1471-1485

STATUTORY AUTHORITY: KRS 194A.050, 200.650-676

NECESSITY, FUNCTION, AND CONFORMITY: The Cabinet for Health Services is directed by KRS 200.650 to 200.676 to administer [~~all~~] funds appropriated to implement provisions, to enter into contracts with service providers, and to promulgate administrative regulations. This administrative regulation establishes [~~sets forth~~] the provisions for evaluation and eligibility policies pertaining to First Steps, Kentucky's Early Intervention Program.

Section 1. Evaluation. (1) A child referred to the First Steps program shall be evaluated [~~Every child shall have an evaluation~~] to determine eligibility.

(2)(a) A determination of eligibility pursuant to Section 2 of this administrative regulation, assessments in the area of delay, in accordance with 911 KAR 2:130, and the initial IFSP team meeting [~~(a) A primary evaluation~~] shall occur within forty-five (45) calendar days after a Point of Entry receives an initial [~~receipt of the~~] referral; or

(b) If a determination of eligibility, assessments and initial IFSP team meeting [~~primary evaluation~~] does not occur within forty-five (45) calendar days due to illness of

the child or a request by the parent, the delay circumstances shall be documented.

(c) If [~~When~~] a family is referred for a determination of eligibility [~~evaluation by the initial service coordinator~~] and the family is under court order or a social services directive to enroll their child in First Steps, the court or social service agency shall be informed within three (3) working days by the initial service coordinator, if the family refuses to participate in the determination of eligibility [~~evaluation~~].

(3) [~~(d)~~] Child records of evaluations transferred from out-of-state tertiary or developmental evaluation centers shall be reviewed by the initial service coordinator and shall be utilized for eligibility determination if [~~when~~]:

(a) [~~1.~~] The records meet First Steps evaluation time lines established in subsection (4)(a) of this Section; and

(b) [~~2.~~] The records contain the [~~all~~] developmental evaluation information established in subsection (10)(a) and (b) of this Section ~~required by First Steps to determine eligibility~~].

(4) [~~(2)~~] The primary level evaluation is the first level in the First Steps evaluation system that shall be utilized to determine eligibility, developmental status and recommendations for program planning:

(a) If there is a previous [~~The~~] primary level evaluation [~~is used when there are no existing evaluations~~] available, it shall have been performed within the following allowed time limits:

1. For children under twelve (12) months of age, evaluations shall have been performed within three (3) months prior to referral to First Steps;

2. For children twelve (12) months to three (3) years of age, evaluations shall

[~~must~~] have been performed within six (6) months prior to referral to First Steps;

(b) Primary level evaluations shall provide evaluation in the [~~all~~] five (5) developmental areas identified in Section 2(1)(a)1. through 5. using norm referenced standardized instruments;

(c) The primary level evaluation shall be provided by a multidisciplinary team consisting of a physician or nurse practitioner and a primary evaluator approved by the cabinet;

(d) A primary level evaluation shall [~~be multidisciplinary and shall minimally~~] include:

1. A medical component completed by a physician or a nurse practitioner that includes:

a. A history and physical examination;

b. A hearing and vision screening; and

c. A child's medical evaluation that shall be current in accordance with paragraph (a) of this subsection [~~according to the following:~~

~~(i) For children under twelve (12) months of age, the medical evaluation shall have been performed within three (3) months prior to referral to First Steps; and~~

~~(ii) For children twelve (12) months to three (3) years of age, the medical evaluation shall be performed within six (6) months prior to referral~~];

2. A developmental component completed by a CCSHCN approved [~~a qualified~~] primary level evaluator that utilizes norm referenced standardized instruments, [~~measures and~~] the results of which shall:

a. Include the determination of eligibility or possible referral for a record review;

and

b. Be discussed with [~~interpreted to~~] the family prior to the initial IFSP team meeting and addressed at the initial IFSP meeting with the entire team present.

(5) Prior to the initial IFSP team meeting the Initial Service Coordinator shall contact the family to make appropriate arrangements, including selection of a Primary Service Coordinator and service providers, in accordance with 911 KAR 2:110.

(6) At the initial IFSP team meeting the IFSP team shall:

(a) Verify the child's eligibility;

(b) Review the evaluation information identified in subsection (4) of this Section;

(c) Review the assessment reports in accordance with 911 KAR 2:130; and

(d) Determine the services the child shall receive. [~~(3) Verification of a child's eligibility for services shall be based upon the review by parents and professionals at the initial IFSP meeting;~~]

(7)(a) [~~(4)~~] Reevaluations shall be provided if [~~when~~] a child's eligibility warrants review [~~or a new condition is suspected or becomes apparent;~~

~~(a) The need for reevaluation is determined by the IFSP team;~~

~~(b) Reevaluations shall be obtained at the level of evaluation determined to be needed by the IFSP team~~]**.**

(b) Reevaluations shall not be used to:

1. Address concerns that are medical in nature; or

2. Provide periodic, ongoing follow-up services for post testing or testing for transition.

(c) Based on the result of the reevaluation, the IFSP team shall:

1. Continue with the same level of services; [~~or~~]

2. Continue with modified services;

3. Continue eligibility with a tracking and maintenance approach by the primary discipline and reevaluate in six (6) months; or

4. Transition [~~Graduate~~] the child from First Steps services because the child is developmentally age appropriate [~~; or~~

~~4. Continue eligibility with a tracking and maintenance approach and reevaluate in six (6) months~~].

(8) A review of the child's First Steps record shall be [~~(5) An intensive evaluation is~~] the second level in the First Steps evaluation system that shall be utilized to determine eligibility, medical or mental diagnosis, program planning, or plan evaluation. [~~:~~]

(a) A primary evaluator or the IFSP team shall refer a child's record to the Commission for a record review if [~~A child shall be referred for an intensive level evaluation when~~]:

1. A primary evaluator identifies a need for further developmental testing necessary to clarify a diagnosis to further define the child's developmental status in terms of a child's strengths and areas of need; [~~or~~]

2. A child does not [~~doesn't~~] meet eligibility guidelines at the primary level, but a primary evaluator and [~~or~~] the family still have concerns that the child is developing atypically and a determination of eligibility based on professional judgment [~~judgement~~] is needed; or

3. The IFSP team requests an intensive level [~~team~~] evaluation for the purposes

of a diagnosis or to make specific program planning and evaluation recommendations for the individual child.

(b)1. If a primary evaluator or an IFSP team refers a child's record for a record review the following shall be submitted by the service coordinator to the Louisville Commission office at 982 Eastern Parkway, Louisville, Kentucky, 40217:

a. A cover letter from the service coordinator or evaluator justifying the referral for a record review;

b. Primary level evaluation information specified in subsection (10) of this Section;

c. Assessment reports required in 911 KAR 2:130; and

d. Available IFSPs.

2. The service coordinator or evaluator requesting the record review shall attempt to procure and submit the following information:

a. Birth records, if neonatal or perinatal complications occurred;

b. General pediatric records from the primary pediatrician;

c. Medical records from hospitalizations; and

d. Records from medical sub-specialty consultations, such as neurology, orthopedic, gastroenterology or ophthalmology.

(c)1. Upon receiving a referral, a team of Commission professional staff shall conduct a record review.

2. After conducting the record review, staff shall:

a. Determine that further developmental testing, diagnostics or additional professional judgment are required in order to adequately ascertain the child's

developmental needs, and the Commission shall refer the child for an intensive level evaluation, the third level in the First Steps evaluation system;

b. Determine that the child meets or does not meet the eligibility criteria established in Section 2(1) of this administrative regulation; or

c. Provide the IFSP team with recommendations for service planning.

[~~A record review shall be done by an intensive team at the request of the IFSP team whenever:~~

~~1. There is a question of eligibility;~~

~~2. Concern for a child's condition; or~~

~~3. Effectiveness of a child's program plan.~~]

(d) Upon request of the Commission, a team approved by the Commission and consisting of the following members shall perform an intensive level evaluation [[~~(c)~~] ~~shall be provided by an approved team consisting of~~]:

1. A board certified developmental pediatrician; [~~or~~]

2. A pediatrician who has experience in the area of early childhood development; [~~and~~]

3. A pediatric physiatrist; or

4. A pediatric neurologist; and

5. One (1) or more [~~qualified~~] developmental professionals identified in 911 KAR 2:150, Section 1.

(9) [~~(6)~~] Family rights shall [~~must~~] be respected and procedural safeguards followed in providing evaluation services:

(a) Written parental consent shall be obtained before conducting an evaluation or

assessment by the evaluator or assessor respectively.

(b) If a parent or guardian refuses to allow a child to undergo a physical or medical examination for eligibility because of religious beliefs:

1. Documentation shall be obtained in the form of a notarized statement. The notarized statement shall be signed by the parent or guardian to the effect that the physical examination or evaluation is in conflict with the practice of a recognized church or religious denomination to which they belong.

2. If a child is determined [~~With the presence of a professional judgement of developmental delay that determines the child~~] to be eligible, First Steps shall provide, at the parent's request, services that do not require, by statute, proper physical or medical evaluations.

3. The Initial Service Coordinator shall explain to the family that refusal due to religious beliefs may result in a denial of services which require a medical assessment on which to base treatment protocols.

(10) [~~(7)~~] A written report shall be completed upon completion of an [~~for every level of~~] evaluation [~~including record reviews~~].

(a) A record review shall include the components specified in this paragraph that can be addressed without having the child present for the evaluation. A primary level evaluation and an intensive level evaluation shall include the following components [~~The minimum components are~~]:

1. Date of evaluation;

2. Names of evaluators and those present during the evaluation, professional degree, and discipline;

3. The setting of the evaluation;

4. [~~2.~~] Name and telephone number of contact person;

5. [~~3.~~] Identifying information that includes the:

a. Child's CBIS identification number [~~Age~~];

b. Child's name and address;

c. Child's chronological age (and gestational age, if prematurely born) at the time of the evaluation;

d. Health of the child during the evaluation;

e. [~~b.~~] Date of birth;

f. [~~c.~~] Date of evaluation;

[~~d. Evaluator's affiliation, and professional degree;~~]

g. [~~e.~~] Referral source; and

h. [~~f.~~] Reason for referral or presenting problems.

6. [~~4.~~] Tests administered or evaluation procedures utilized and purpose of instrument. No one (1) method of evaluation shall be used, but a combination of tests and methods shall be used;

7. [~~5.~~] Test results and interpretation of strengths and needs of the child;

8. [~~6.~~] Test results reported in standard deviation or developmental quotient if [~~when such~~] instrumentation is required pursuant to subsection (4)(d)2. of this Section;

9. Factors that may have influenced test conclusions;

10. [~~7.~~] Eligibility;

11. [~~8.~~] Developmental status or diagnosis;

12. [~~9.~~] Program plan recommendations, including suggestions regarding natural

environments, that address the child's holistic needs based on the evaluation;

13. Parent's assessment of the child's performance in comparison to abilities demonstrated by the child in more familiar circumstances; and

14. [~~10.~~] A narrative description of the [~~all~~] five (5) areas of a child's developmental status.[~~;~~]

(b) The [~~full~~] report established in paragraph (a) of this subsection shall be written in clear, concise language that is easily understood by the family.

(c)1. The reports and notification of need for further evaluation shall be made available to the current IFSP team within fourteen 14 calendar [~~ten (10) working~~] days from the date the evaluation referral was received [~~was completed~~].

2. If it is not possible to provide the report and notification required in this paragraph by the established timeframe due to illness of the child or a request by the parent, the delay circumstances shall be documented.

[~~(8) child records of timely evaluations transferred from out of state tertiary centers or developmental evaluation centers may be utilized for eligibility determination;~~

~~(a) These records shall be reviewed for all required evaluation record components by the POE services coordinator;~~]

~~(b) If information is unattainable, the child shall be evaluated for eligibility.~~]

Section 2. Eligibility. (1) A child shall be [~~Children who are~~] eligible for First Steps services if he is aged [~~include those who are ages~~] birth through two (2) years;[~~,~~] and:

(a) Through the evaluation process is [~~By using appropriate diagnostic instruments and procedures or professional judgment, are~~] determined to have fallen significantly behind developmental norms in the following skill areas:

1. Cognitive development;

2. Communication through speech and language development;

3. Physical development including vision and hearing;

4. Social and emotional development; and

5. Adaptive skills development; and

(b) Is [~~Are~~] significantly behind in developmental norms as evidenced by the following criteria:

1. Two (2) standard deviations below the mean in one (1) skill area (developmental quotient equivalent seventy (70) percent or below); or

2. At least one and one-half (1 1/2) standard deviations below the mean in two (2) skill areas; or

(c) Meets the criteria established in KRS 200.654(10)(b) who has one of the following diagnosed conditions:

Aase-Smith syndrome	Alper's syndrome
Aase syndrome	Amelia
Acrocallosal syndrome	Angelman syndrome
Acrodysostosis	Aniridia
Acro-Fronto-Facio-Nasal Dysostosis	Anophthalmia/Microphthalmia
Adrenoleukodystrophy	Antley-Bixler syndrome
Agenesis of the Corpus Callosum	Apert syndrome
Agyria	Arachnoid cyst with neuro-developmental delay
Aicardi syndrome	
Alexander's Disease	Arhinencephaly

Arthrogryposis
Ataxia
Atelosteogenesis
Autism
Baller-Gerold syndrome
Bannayan-Riley-Ruvalcaba syndrome
Bardet-Biedl syndrome
Bartsocas-Papas syndrome
Beals syndrome (congenital contractural arachnodactyly)
Biotinidase Deficiency
Bixler syndrome
Blackfan-Diamond syndrome
Bobble Head Doll syndrome
Borjeson-Forssman-Lehmann syndrome
Brancio-Oto-Renal (BOR) syndrome
Campomelic Dysplasia
Canavan Disease
Carbohydrate Deficient Glycoprotein syndrome
Cardio-Facio-Cutaneous syndrome
Carpenter syndrome
Cataracts - Congenital

Caudal Dysplasia
Cerebro-Costo-Mandibular syndrome
Cerebellar Aplasia/Hypoplasia/Degeneration
Cerebral Atrophy
Cerebral Palsy
Cerebro-oculo-facial-skeletal syndrome
CHARGE Association
Chediak Higashi syndrome
Chondrodysplasia Punctata
Christian syndrome
Chromosome Abnormality a. unbalanced numerical (autosomal) b. numerical trisomy (chromosomes 1-22) c. sex chromosomes XXX; XXXX; XXXXX;XXXY; XXXXY
CNS Aneurysm with Neuro-Developmental Delay
CNS Tumor with Neuro Developmental Delay
Cockayne syndrome
Coffin Lowry syndrome
Coffin Siris sydrome

Cohen syndrome
Cone Dystrophy
Congenital Cytomegalovirus
Congenital Herpes
Congenital Rubella
Congenital Syphilis
Congenital Toxoplasmosis
Cortical Blindness
Costello syndrome
Cri du chat syndrome
Cryptophthalmos
Cutis Laxa
Cytochrome-c Oxidase Deficiency
Dandy Walker syndrome
DeBarsy syndrome
DeBuquois syndrome
Dejerine-Sottas syndrome
DeLange syndrome
DeSanctis-Cacchione syndrome
Diastrophic Dysplasia
DiGeorge syndrome (22q11.2 deletion)
Distal Arthrogryrosis
Donohue syndrome

Down syndrome
Dubowitz syndrome
Dyggve Melchor-Clausen syndrome
Dyssegmental Dysplasia
Dystonia
EEC (Ectrodactyly-ectodermal dysplasia-clefting) syndrome
Encephalocele
Encephalo-Cranio-Cutaneous syndrome
Encephalomalacia
Exencephaly
Facio-Auriculo-Radial dysplasia
Facio-Cardio-Renal (Eastman-Bixler) syndrome
Familial Dysautonomia (Riley-Day syndrome)
Fanconi Anemia
Farber syndrome
Fatty Acid Oxidation Disorder (SCAD, ICAD, LCHAD)
Femoral Hypoplasia
Fetal Alcohol syndrome/Effects
Fetal Dyskinesia

Fetal Hydantoin syndrome	Hemorrhage-Intraventricular Grade III, IV
Fetal Valproate syndrome	Hereditary Sensory & Autonomic Neuropathy
Fetal Varicella syndrome	
FG syndrome	Hereditary Sensory Motor Neuropathy (Charcot Marie Tooth Disease)
Fibrochondrogenesis	
Floating Harbor syndrome	Herrmann syndrome
Fragile X syndrome	Heterotopias
Fretman-Sheldon (Whistling Facies) syndrome	Holoprosencephaly (Aprosencephaly
	Holt-Oram syndrome
Fryns syndrome	Homocystinuria
Fucosidosis	Hunter syndrome (MPSII)
Glaucoma - Congenital	Huntington Disease
Glutaric Aciduria Type I and II	Hurler syndrome (MPSI)
Glycogen Storage Disease	Hyalanosis
Goldberg-Shprintzen syndrome	Hydranencephaly
Grebe syndrome	Hydrocephalus
Hallermann-Streiff syndrome	Hyperpipecolic Acidema
Hays-Wells syndrome	Hypomelanosis of ITO
Head Trauma with Neurological Sequelae/Developmental Delay	Hypophosphotasia-Infantile
	Hypoxic Ischemic encephalopathy
Hearing Loss (Bilateral > 40 dB)	I-Cell (mucolpidosis II) Disease
Hemimegalencephaly	Incontinentia Pigmenti
Hemiplegia/Hemiparesis	Infantile spasms

Ininencephaly	Leukodystrophy
Isovaleric Acidemia	Lissencephaly
Jarcho-Levin syndrome	Lowe syndrome
Jervell syndrome	Lowry-Maclean syndrome
Johanson-Blizzard syndrome	Maffucci syndrome
Joubert syndrome	Mannosidosis
Kabuki syndrome	Maple Syrup Urine Disease
KBG syndrome	Marden Walker syndrome
Kenny-Caffey syndrome	Marshall syndrome
Klee Blattschadel	Marshall-Smith syndrome
Klippel-Feil Sequence	Maroteaux-Lamy syndrome (MPS VI)
Landau-Kleffner syndrome	Maternal PKU Effects
Lange-Nielsen syndrome	Megalencephaly
Langer Giedion syndrome	MELAS
Larsen syndrome	Meningocele (cervical)
Laurin-Sandrow syndrome	MERRF
Leber's Amaurosis	Metachromatic Leukodystrophy
Leigh Disease	Metatropic Dysplasia
Lennox-Gastaut syndrome	Methylmalonic Acidemia
Lenz Majewski syndrome	Microcephaly
Lenz Microophthalmia syndrome	Microtia-Bilateral
Levy-Hollister (LADD) syndrome	Midas syndrome
Lesch-Nyhan syndrome	Miller (postaxial acrofacial-Dysostosis)

syndrome	Ocular Albinism
Miller-Dieker syndrome	Oculocerebrocutaneous syndrome
Mitochondrial Disorder	Oculo-Cutaneous Albinism
Moebius syndrome	Optic Atrophy
Morquio syndrome (MPS IV)	Optic Nerve Hypoplasia
Moya-Moya Disease	Oral-Facial-Digital syndrome Type I-VII
Mucolipidosis II, III	Osteogenesis Imperfecta Type III-IV
Multiple congenital anomalies (major organ birth defects)	Osteopetrosis (Autosomal Recessive)
	Oto-Palato-Digital yndrome Type I-II
Multiple Pterygium syndrome	Pachygyria
Muscular Dystrophy	Pallister Mosaic syndrome
Myasthenia Gravis - Congenital	Pallister-Hall syndrome
Myelocystocele	Pelizaeus-Merzbacher Disease
Myopathy - Congenital	Pendred's syndrome
Myotonic Dystrophy	Periventricular Leukomalacia
Nager (Acrofacial Dysostosis) syndrome	Pervasive Developmental Disorder
Nance Horan syndrome	Peters Anomaly
NARP	Phocomelia
Neonatal Meningitis/Encephalitis	Pierre Robin Sequence
Neuronal Ceroid Lipofuscinoses	Poland Sequence
Neuronal Migration Disorder	Polymicrogyria
Nonketotic Hyperglycinemia	Popliteal Pterygium syndrome
Noonan syndrome	Porencephaly

Prader-Willi syndrome	Seckel syndrome
Progeria	Septo-Optic Dysplasia
Propionic Acidema	Shaken Baby syndrome
Proteus syndrome	Short syndrome
Pyruvate carboxylase Deficiency	Sialidosis
Pyruvate Dehydrogenase Deficiency	Simpson-Golabi-Behmel syndrome
Radial Aplasia/Hypoplasia	Sly syndrome (MPS VII)
Refsum Disease	Smith-Fineman-Myers syndrome
Retinoblastoma	Smith-Limitz-Opitz syndrome
Retinoic Acid Embryopathy	Smith-Magenis syndrome
Retinopathy of Prematurity Stages III, IV	Sotos syndrome
Rett syndrome	Spina Bifida (Meningomyelocele)
Rickets	Spinal Muscular Atrophy
Rieger syndrome	Spondyloepiphyseal Dysplasia Congenita
Roberts SC Phocomelia	Spondylometaphyseal Dysplasia
Robinow syndrome	Stroke
Rubinstein-Taybi syndrome	Sturge-Weber syndrome
Sanfilippo syndrome (MPS III)	TAR (Thrombocytopenia-Absent Radii syndrome)
Schinzel-Giedion syndrome	
Schimmelpenning syndrome (Epidermal Nevus syndrome)	Thanatophoric Dysplasia
	Tibial Aplasia (Hypoplasia)
Schizencephaly	Toriello-Carey syndrome
Schwartz-Jampel syndrome	Townes-Brocks syndrome

Treacher-Collins syndrome	Weaver syndrome
Trisomy 13	Wiedemann-Rautenstrauch syndrome
Trisomy 18	Williams syndrome
Tuberous Sclerosis	Winchester syndrome
Urea Cycle Defect	Wolf Hirschhorn syndrome
Velocardiofacial syndrome (22q11.2 deletion)	Yunis-Varon syndrome
Wildervanck syndrome	Zellweger syndrome
Walker-Warburg syndrome	

[~~3. Children may be determined to be developmentally delayed by professional, clinical judgement in the event~~] If ~~standard deviation scores are inconclusive and evaluation reveals the child has significant atypical development or quality or pattern of development, or further diagnostic evaluation is needed to address concerns related to the five (5) areas of development. Professional judgement to determine a child to be developmentally delayed shall be obtained from an approved evaluator; or~~

~~(2) Those Children who are diagnosed with physical or mental conditions which have a high probability of resulting in developmental delay and the diagnosis has been specified by KRS 200.645(10) as an established risk condition. The developmental delay shall be within one (1) of the following categories:~~

~~(a) Chromosome abnormalities associated with developmental delay;~~

~~(b) Recognizable yndromes associated with developmental delay;~~

~~(c) Abnormality in central nervous system;~~

~~(d) Neurological or neuromuscular disorders associated with developmental~~

~~delay;~~

~~(e) Symptomatic intrauterine infection or neonatal central nervous system infection;~~

~~(f) Sensory impairments that result in significant visual or hearing loss, or a combination of both, interfering with the ability to respond effectively to environmental stimuli;~~

~~(g) Metabolic disease having a high likelihood of being associated with developmental delay, even with treatment;~~

~~(h) Maternal teratogen exposure at a level known to have a high risk for developmental delay;~~

~~(i) Behavioral or emotional disorders associated with extreme excesses or deficits which inhibit function;~~

~~(j) Central nervous system malignancy or trauma resulting in developmental delay.~~]

(2) [~~(3)~~] If a child referred to the First Steps program was born at less than thirty-seven (37) weeks gestational age, the following shall be considered [~~Eligibility for a premature child shall consider~~]:

(a) The chronological age of infants and toddlers who are less than twenty-four (24) months old shall be corrected to account for premature birth;

(b) Correction for prematurity is not appropriate for children born prematurely whose chronological age is twenty-four (24) months or greater.

(c) Documentation of prematurity shall include a physician's [~~physician~~], or nurse practitioner's [~~practitioner,~~] written report of gestational age and a brief medical history.

(d) Evaluation reports on premature infants and toddlers shall include test scores calculated with the use of both corrected and chronological ages.

Section 3. The provisions of this administrative regulation shall be effective with services provided on or after June 15, 2002